

**National Institute on Aging (NIA)
Behavioral and Social Research Program**

**Data Priorities for Behavioral and Social
Research on Aging**

Committee Report

November 2007

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**National Institute on Aging (NIA)
Behavioral and Social Research Program (BSR)**

**Data Priorities for Behavioral and Social
Research on Aging**

I. Background and Charge to the Committee

Writing in 2004, the National Advisory Council on Aging (NACA) subcommittee reviewing the Behavioral and Social Research (BSR) program considered data collection “one of the stellar achievements of BSR over the last decade.” Nevertheless, the size of the National Institute on Aging (NIA) investment in data collection, the need to support a growing array of interdisciplinary studies in aging, and the changing technology and environment for data collection and archiving all raise new issues for the BSR. To address these issues, the BSR convened the *Committee on Data Priorities for Behavioral and Social Research on Aging* in 2006–2007.

Although the task of the Committee was similar to that of the *Ad Hoc Advisory Group on the NIA Extramural Priorities for Data Collection in Health and Retirement Economics*, which was convened 20 years ago, the Committee members were asked to consider several distinct changes in the BSR environment since that time:

- Many more large panel studies in the BSR portfolio, versus only a few in 1987;
- Greater program integration within the NIA and the National Institutes of Health;
- Greater emphasis on multidisciplinary and interdisciplinary research;
- Greater expectation and evidence of data sharing; and
- Changes to the funding model.

Another critical development in the last two decades is the spawning of international studies modeled on the Health and Retirement Study (HRS). Thus, Committee recommendations were sought regarding where and how the BSR should allocate its funding, as well as how to balance the need for study standardization with the appropriate flexibility for cross-cultural application. For domestic research, the BSR solicited Committee input on the size and types of studies the BSR should fund. The Committee was encouraged to consider opportunities for investment beyond surveys; for instance, smaller studies with innovative methods which could be applied to large surveys and life course studies. Finally, the Committee was asked to establish priorities for its recommendations which will take into account the limited funds available for implementation.

The Committee’s charge was threefold:

- Review current data collection, archiving, and dissemination funded by the NIA/BSR;
- Assess likely data infrastructure needs for behavioral and social research on aging in the next 10–15 years; and
- Recommend priorities for NIA/BSR investment in data.

The 14 Committee members comprise research leaders in health policy, economics, epidemiology, and other disciplines relevant to behavioral and social research (see *Appendix A* for a biographical sketch of each member). Additionally, an independent contractor, Rose Li and Associates, Inc., was retained by the NIA to provide review services that include assisting in Committee management, helping BSR staff compile requested information and materials for Committee memos, documenting meeting proceedings, and drafting the final report.

This report is the product of the Committee's deliberations; it describes the process by which the Committee answered its charge and contains its recommendations to Richard Suzman, Director of the BSR Program.

II. Process Undertaken by the Committee

A. Solicitation of Feedback

Several professional societies were invited to provide input regarding data priorities and the review process. A letter was received from the Population Association of America. Since 2006, individuals have been encouraged to provide public comments online, via E-mail, or by letter (See <http://www.roseliassociates.com/BSRDataReview>).

B. Initial Committee Meeting

The Committee's initial in-person meeting was held on September 19-20, 2006, in Washington, DC.¹ In addition to Committee members, attendees included staff members from BSR, the U.S. Census Bureau Aging Studies Branch, and the Committee on National Statistics of the National Academies. At the start of the meeting, Committee members received a binder prepared by BSR staff containing pertinent materials for the ensuing discussion. The book included memoranda prepared by BSR staff; descriptions of and excerpts from NIA/BSR-funded studies; research articles, conference proceedings, and reports; and recent National Academy of Sciences (NAS) recommendations that are relevant to the Committee's charge. (See *Appendix B* for a complete list of book contents; all materials are available upon request from BSR.)

The meeting agenda and associated binder were organized around nine important aging-related research topics which were identified by BSR staff, with input from the Committee co-chairpersons:

1. International and cross-national surveys
2. Data dissemination and archiving
3. Life course studies
4. Disability dynamics and frailty
5. Mortality
6. Retirement and health economics
7. Psychological development
8. Cognition
9. Health status, outcomes, and disparities

¹ Eileen Crimmins was unable to attend.

BSR Director Richard Suzman provided opening remarks and BSR Deputy Director John Haaga reviewed the Committee's charge, introduced the topic areas, and outlined the process and expectations for the Committee's work. Co-chairpersons James Smith and Lisa Berkman offered their perspectives on the current state of behavioral and social research on aging and invited Committee members to identify "glaring gaps" in the data portfolio which should be addressed in order to propel aging research forward over the next several decades.

The meeting then proceeded as a series of sessions facilitated by two to three designated discussion facilitators, who were prompted with questions (contained in the meeting agenda), to which they responded in their opening remarks. Some facilitators offered additional issues for the Committee to consider in its discussion of the topic at hand. These discussions typically resulted in the formulation of emerging recommendations; in some instances, Committee members requested that additional information be gathered or other experts consulted to inform their recommendations. Additional expertise was deemed particularly critical in the areas of cognition and biomarkers and genetics. Committee members also asked for the following:

- "...information about (1) the cost incurred by the Panel Study on Income Dynamics (PSID) to improve accessibility to its databases; (2) the data sharing approach used by the English Longitudinal Study of Ageing (ELSA); (3) the definition of 'user-friendly' data (e.g., undergraduate accessibility); and (4) whether studies that represent BSR's major investments are sufficiently documented and accessible."
- "...details of older or lesser known candidate studies [i.e., panel studies that might be turned into synthetic cohorts, or followed up as they approach old age]..."
- "...opportunities and barriers to accessing Social Security Administration (SSA) data, and ...how Medicare data can be used in the interim."
- "...the possibility of adding on to existing studies versus initiating new studies, investing in cross-sectional studies that might become longitudinal studies, and related issues..."

At the conclusion of the meeting, Haaga summarized the emerging recommendations proposed by Committee members throughout the meeting and proposed action items in terms of staff work. Before closing, Committee members were invited to individually reiterate what they considered to be glaring gaps in the data, based on the previous two days' discussion.

C. NIA/BSR Staff Work

NIA/BSR received an NIH Evaluation Express award to evaluate the impact of data activities during 1994-2004, covering the full range of disciplines and interdisciplinary fields represented in the BSR portfolio. BSR staff compiled or generated information in response to questions raised by the Committee during the first meeting. These activities included culling recommendations from recent NAS/IOM reports concerning specific topics of interest; convening subgroup teleconferences to expand the pool of experts on targeted topics; and preparing memoranda related to:

- cohort studies;
- current status of the NLTCs;
- nursing home and home health data;
- HRS methods of adapting to new content and opportunities; and
- preliminary findings from an evaluation of publications using BSR-funded data sets.

D. Subgroup Teleconferences

Given the Committee's sense that additional expertise was needed to inform deliberations in the areas of (1) cognition and (2) biomarkers and genetics, *ad hoc* subgroups focusing on these topics were convened by teleconference, as described below. The general goal for these subgroups was to discuss possible recommendations for the Committee to consider, sharpen the points of contention where there is no agreement, and suggest specific directions for research before the full Committee meeting. A few days following each teleconference, notes were circulated to the subgroup for review and input, including to those members who were not present, for comment and extension.

Subgroup on Cognitive Data Needs

Chaired by Committee member Jack McArdle, the purpose of this subgroup was to discuss needs and opportunities for collecting cognitive data in panels and household surveys to support behavioral and social research on aging.² Subgroup participants received a set of background materials prior to the teleconference (held May 1, 2007) that included a description of the Committee's charge and excerpts from the September 2006 meeting summary; a memorandum on datasets for the study of cognitive aging which provided examples of studies that BSR currently is supporting; and relevant excerpts from the 2004 NACA review of the BSR program.

During the teleconference, participants considered the following topics, on which the Committee on Data Priorities sought input:

- aging-related cognitive changes
- early predictors of cognitive ability in later life
- socially situated and collective cognition
- healthy cognitive aging

Discussion then turned to potential models for studying cognition in aging – i.e., cohort or longitudinal studies, following families, or genetically informed designs. Attendees also discussed broadening the domain of cognitive measures represented in surveys. Finally, participants offered a number of recommendations regarding methodology, measurement, and resource sharing. Some recommendations were added or elaborated upon in follow-up e-mails from teleconference participants. A summary of this subgroup's teleconference was included in the May 20-21, 2007 meeting binder.

Subgroup on Genetics Data Needs

This subgroup, chaired by Committee member Kenneth Wachter, convened to discuss needs and opportunities for genetic epidemiology and social-behavioral genetic research related to aging.³ In advance of the teleconference (held May 10, 2007), participants were provided with the Committee's charge, excerpts from the September 2006 meeting summary, and portions of the 2004 NACA review of the BSR program related to behavioral genetics and biodemography.

² The teleconference participants consisted of Jack McArdle (Chair), Lisa Berkman, Scott Hofer, Margie Lachman, Timothy Salthouse, James Smith, and NIA staff (Richard Suzman, John Haaga, Lis Nielsen, and Rose Li).

³ The teleconference participants consisted of Kenneth Wachter (Chair), Kaare Christensen, Eileen Crimmins, David Laibson, Matthew McGue, Burton Singer, George Vogler, and NIA staff (John Haaga, Jennifer Harris, David Reiss, Erica Spotts, and Rose Li).

The subgroup discussion began with a consideration of research questions raised by the Committee. These included which phenotypes should be the focus of study, whether genetic data should be used to inform interpretation of results, and how epigenetic studies may be relevant to BSR data collection. Among other topics related to measurement and methodology, the subgroup discussed measuring environmental factors and the advisability of investing in the collection and archiving of biological materials, which is an area of key interest to the Committee. The subgroup also considered the role of program announcements in encouraging genetic data collection. In conclusion, the subgroup endorsed the current direction of BSR-funded research in this arena and offered no recommendations for major change. A summary of this teleconference was included in the May 20-21, 2007 meeting binder.

E. Second In-Person Committee Meeting

The Committee on Data Priorities for Behavioral and Social Research on Aging was reconvened for a final in-person meeting on May 20–21, 2007, in Bethesda, Maryland.⁴ Members received a comprehensive binder prepared by BSR staff which contained materials and information that had been requested during the last meeting, as well as the summaries of the September 2006 meeting and the intervening subgroup teleconferences. Examples of materials contained in the binder include recommendations from recent NAS/Institute of Medicine reports, memoranda to the Committee on topics for which more information was requested (i.e., NLTC status, cohort studies), a sample informed consent form for biological material collection within a survey, and information on archiving and access procedures for data from ongoing surveys. (See *Appendix C* for a complete list of binder contents; all materials are available upon request from BSR.)

The agenda topics for this meeting, which reflected a sharper focus, based on conclusions derived from the September 2006 meeting, were as follows:

- Cohort studies
- International and cross-national research
- Cognition and personality
- Biomarkers and genetics
- Disability dynamics and frailty
- Data sharing
- Data dissemination and archiving.

Designated discussion facilitators opened each session, followed by group discussion.

On the second day of the meeting, several Federal agency representatives gave presentations. One set of presentations related to issues regarding data sharing. Miron Straf of the National Academies' Division of Behavioral and Social Sciences and Education reviewed NAS studies related to privacy of participants and confidentiality of data in behavioral and social research as far back as 1979. He also mentioned studies in development, including the NIA-supported joint NAS Committee on National Statistics and Committee on Population (CPOP) panel on data sharing for population studies which collect biological samples. Barney Cohen, CPOP Director, provided greater detail on this panel's work, which will cover issues of informed consent, confidentiality, archiving, and access. The goal of the panel is to develop best practices that will

⁴ Jack McArdle participated by telephone; Thomas Cook was unable to attend.

assist survey groups in coordinating their data sharing procedures. Finally, Haaga briefed the Committee on the 2006 Data Sharing Genetics Workshop, which will inform the development of interim guidelines pending further development of NIH-wide guidelines and the report from the NAS workshop.

The second set of presentations highlighted the plans or perspectives of other Federal agencies that are collecting data on aging. Ed Sondik, Director of the National Center for Health Statistics (NCHS), reported on the principal activities of his agency and discussed what he considers critical variables in priority setting. He emphasized that budgetary constraints threaten continuation of NCHS activities at their current level and the need for major changes to free up scarce resources. Howard Hogan of the U.S. Bureau of the Census provided updates on the state of the Bureau's leadership, recent changes in the administration of the national census, and domestic (i.e., Survey of Income and Program Participation, Dynamics of Economic Well-Being System) and international activities.

BSR staff also updated the Committee on the status of the National Long-Term Care Survey (NLTC) and requested their feedback. In brief, the NIA published a notice of intent in October, 2006 to issue a Request For Applications (RFA) to continue the NLTC under the cooperative agreement mechanism. The notice referenced two NAS meetings at which the future of the NLTC was discussed. Based on these meetings, the recommendation made to the NIA was to continue support for the NLTC through an RFA, with two goals: (1) To field a 2009 wave of the NLTC, collecting the most critical updates needed to preserve the rich trend data, and to make the data publicly available; and (2) to redesign the NLTC beyond the 2009 wave. To pursue the RFA, the identifiable data were to be transferred to the National Archive of Computerized Data on Aging (NACDA), a move approved by the institutional review board at Duke Medical School (the current awardee). However, this decision was overturned by Duke's legal counsel in mid-December 2006, and the RFA was not published. The BSR now is engaged in discussions with Duke Medical School and the U.S. Census Bureau (which has been the data collection agency for the NLTC) on how to facilitate an open competition for the next wave. The Committee discussed these events and offered some advice for the future of the NLTC, which is described in Section III of this report, *Committee Recommendations*.

The remainder of the meeting was devoted to formulating specific recommendations for this final report. Co-chairpersons James Smith and Lisa Berkman suggested several topic areas under which to group recommendations, which were further refined and added to by Committee members. The group then engaged in focused discussion to refine its recommendations. A draft of the recommendations was circulated to Committee members shortly after the May 2007 meeting for additional comments and discussion, and underwent a series of revisions during the summer of 2007. The final recommendations are presented in the following section.

III. Committee Recommendations

The Committee on Data Priorities for Behavioral and Social Research on Aging offered six primary recommendations for consideration by the NIA and BSR. Though presented under distinct topic areas, these groupings do not preclude the many obvious linkages among the recommendations.

Recommendation 1: The NIA/BSR should enhance efforts to understand the life course and the role of cumulative exposures in aging-related outcomes, by (a) emphasizing longitudinal data collection beginning at younger ages and (b) where possible, collecting retrospective data from older cohorts.

In the Committee's view, the lack of sequential birth cohort studies in the United States which truly integrate biological, social and economic, and environmental data on individuals followed through most and eventually the entire life course, is a glaring gap. A great deal can be learned from the analysis of large, representative cohorts from other countries, such as the British 1946 and 1958 cohorts (and, in the course of time, the 1970 and Millennium cohorts), as they approach old age. However, environments differ in potentially instructive ways – i.e., not all the cohorts in other countries have been affected to the same degree by the obesity epidemic. Had this Committee (or for that matter, NIA) existed in 1946, it might well have recommended a parallel effort in the United States, with nationally representative cohorts established approximately every ten years to provide the basis for comparative studies of age, period, and cohort effects on health and aging, at multiple levels.

Failing that, the Committee recommended that at present the NIA/BSR use a combination of short- and long-term approaches to provide the infrastructure for biologically informed social and behavioral studies of aging. These could include:

- Adding aging-related modules to birth cohort studies that are just beginning;
- “Revitalizing” cohorts with rich biological or environmental data created for other research purposes;
- Extending the life course observation period of older cohorts by beginning sampling at earlier ages; and
- Gathering retrospective data (both recall data and information from administrative records including vital statistics) from older cohorts in ongoing studies.

These approaches could collectively produce a balanced portfolio of studies, covering birth cohorts which are already well advanced in age, as well as others reaching adulthood in the decades to come.

As the most accessible and most widely used instrument for researchers in the demography and economics of aging, the Health and Retirement Study is an invaluable and central source for research into the social and behavioral aspects of aging. The Committee underscored the importance of maintaining this key component of the data system; they also recommended supporting the development of innovative adaptations, as the leaders of the survey begin to pursue them.

Studies covering midlife are extremely useful for this purpose, especially for early indicators of disability through cognitive and mobility pathways, and the development of health disparities at

older ages. These issues also may be addressed by including younger participants in studies designed for older cohorts. The NIA/BSR should support collecting retrospective data (both recall data and administrative records) from studies that may have begun their monitoring at older ages. Examples would include but are not limited to the Panel Study of Income Dynamics (PSID) and the HRS.

Repeated cross-sectional designs are insufficient for answering vital questions about disability dynamics and changing living situations at older ages. Although valuable for other scientific purposes, longitudinal studies which subjects enter at younger ages are unlikely to include (or retain) a large enough sample of the oldest and frailest respondents to support in-depth study of the later stages of the disability process. The Committee encourages efforts to ensure that a redesigned National Long-Term Care Survey, or a successor survey, will provide data on large enough samples, tracked sufficiently often, to support studies of disability dynamics at older ages adequately enough to enable investigation of sub-group differences.

The National Children's Study (NCS), a nationally representative prospective study of more than 100,000 children to be followed from birth until age 21 across the United States, provides an unparalleled opportunity to collect information from early life experiences that can have an impact on later life development. The NCS is funded by a consortium of federal agency partners, including the National Institute of Child Health and Human Development (NICHD) and other NIH Institutes and Centers, the Centers for Disease Control and Prevention, the Department of Education, and the U.S. Environmental Protection Agency. The Committee recommends that the NIA make a serious effort to ensure that data collection for the NCS include information about the children's family and socio-economic contexts to ensure that the study will be useful in future years for analyses of early-life determinants of adult outcomes. From the viewpoint of aging studies, this is obviously a long-term investment, and the NIA would have to determine the appropriate timing for involvement in this large and complex effort. In the shorter term, the Committee also urged NIA/BSR to explore opportunities for promoting the supplemental collection of data from and about the parents and grandparents connected to the children in the NCS, which could facilitate possible analyses of intergenerational influences on health.

Other potentially valuable sources of early- and mid-life data are the birth cohorts or other long-term longitudinal studies (such as occupational cohorts) being initiated in other countries. The Committee underscored the importance of coordinating with these survey teams to increase comparability between U.S. and international data on cohorts.

The NIA/BSR also should consider extending the data sets of younger cohorts initiated by other agencies as the participants age into early adulthood and midlife. Of special interest are the family of cohorts in the National Longitudinal Survey (especially the NLS-Youth); studies within the National Education Longitudinal Studies (NELS) Program, which includes the National Longitudinal Study of the High School Class of 1972 (NLS-72) and High School and Beyond (HS&B); and the Wisconsin Longitudinal Study. In the longer term, the National Longitudinal Study of Adolescent Health (Add Health) is considered to have great potential value for aging studies, especially since useful cognitive measures are being added to the current wave of data collection. Also of interest are the Early Childhood Longitudinal Studies which follows birth (ECLS-B) and kindergarten (ECLS-K) cohorts through kindergarten entry and

eighth grade, respectively, and the Collaborative Perinatal Project, of which several sub-samples have been tracked as they reach ages 40-50.

The Committee identified a host of studies that were initiated to answer specific research questions, which may prove valuable for aging studies in light of their rich biological and environmental data. These include the Coronary Artery Risk Development in Young Adults (CARDIA), the Cardiovascular Health Study, the Bogalusa Heart Study, the Jackson Heart Study, MacArthur Study of Mid-Life, the Reykjavik Study (now the Icelandic Heart Association's Age, Gene, Environment, Susceptibility [AGES] Study), the Helsinki cohort, the African American Health Study in St. Louis, and the Project on Human Development in Chicago Neighborhoods. Some of these study cohorts are in danger of ending, because the initiating institution cannot continue support for the study. An investment in such studies by the NIA/BSR could preserve these well-characterized cohorts for use by researchers in aging. Support for these studies should only be considered if procedures have been established to place the data in the public domain.

The NIA/BSR also should consider soliciting applications that propose to continue the collection, archiving, and analysis of data in existing small cohort studies with rich environmental or phenotypic data which could serve as valuable resources for behavioral and social research on aging.

Recommendation 2: The NIA/BSR should continue to emphasize data collection on contextual (e.g., societal, institutional) factors.

Cross-national comparative research and comparative work within the U.S. will require not only survey micro-data but also an investment in obtaining rich information on the institutional and demographic context of the countries and areas involved, including relevant data from a range of topic areas, such as

- healthcare systems and costs
- labor force participation, labor market features, and pension systems
- disability programs
- long-term care support

NIA/BSR should consider supporting efforts to collect standardized contextual information on the countries in which retirement and health studies are being conducted. Such a data set should go beyond the verbal descriptions commonly included in compendia from international agencies – e.g., it should provide algorithms for coding variables, comparable to those created by the National Bureau of Economic Research (NBER) project on cross-national pensions. These would show, for example, which options for disability payments were available to older workers, with specified conditions in different places over time. These data should be available for public use and would be especially useful in examining contextual variations at the local, state, and cross national levels.

The NIA is interested in the determinants and consequences of health and aging, and the ways in which the health care system (not just medical care) shapes the distribution of health and responds to the needs of an aging society. Perhaps the most important policy issue facing the

United States today is the rising cost of health care. The Committee endorses research on health care and health care costs, and how health care might be provided more efficiently. In particular, it will be important to consider the future direction of health care technology and how it will affect both health outcomes and health care costs, particularly as Baby Boomers retire. A special emphasis on the health of pre-retirees and the Medicare program should be considered. The HRS is in the process of matching its data to Medicare claims data, but Medicare data are available only for respondents after they turn 65. Less is known in any survey about the medical history of people in their 50s and early 60s, a period when many are first affected by serious illness. Nor does any survey include detailed contextual information about the local health care system in which each individual seeks health care – i.e., whether respondents live near a “high-tech” hospital or the quality of attending physicians.

Additional data options may be necessary for studies focusing on specific technological advancements. For example, hip or knee replacements, spine surgery, and implantable defibrillators are sufficiently uncommon that larger sample frames may be necessary to characterize the influence of such innovations on health care costs and patient functioning. Although there was great interest in a deeper investigation of the cost-benefit analysis of healthcare, the Committee recognized the enormous effort required to evaluate new technology and to conduct trials of healthcare intervention, and they were uncertain about the appropriate level of NIA involvement.

The Committee strongly endorsed NIA/BSR startup funding for HRS-like surveys around the world; they considered such support vital to ensuring international data harmonization and sharing. They also felt that additional NIA/BSR funds for data collection may be merited in very large countries whose aging potentially affects the world (e.g., China and India) and in countries where policy change, rapid population aging, exceptional longevity, contrasting disease patterns, or other characteristics are of special value for cross-national comparative research. An important aspect of this research would be targeting those countries that are able to produce high-quality, comparable data *and* are willing to commit to making their data available to researchers; BSR support should be considered only if the data are placed in the public domain for international researchers.

Recommendation 3: The NIA/BSR should increase emphasis on integrating biological pathways and interactions into social, psychological, and behavioral models.

The Committee urged the NIA/BSR to enrich surveys with social and physical environment data and behavioral phenotypes, in order to provide data for studies of gene-environment interactions in aging, and also to encourage development of new analytic methods. The NIA/BSR should support meritorious applications which improve understanding and measurement of environmental factors (at individual, household, and community levels). The influence of social and other environmental factors on biology can be evaluated on multiple levels, including phenotype to physiology to telomeres.

The NIA/BSR also should encourage the collection and banking of genetic data for a wide variety of longitudinal studies (especially those from which the highest attrition is likely in the near term). In addition, these data should be appropriately integrated with social science

research. Breakthroughs in genomic research during the next decade, as well as ever more efficient and less expensive assays, are likely to make this a sound investment. The comparative advantage of NIA/BSR-funded studies among genome biobanks is that they are more representative of large populations. In the future, NIA/BSR-funded surveys could be especially valuable for replicating findings from small, non-representative cohorts in population-based samples, thereby increasing the robustness of such effects or revealing claims that are not generalizable.

The time is ripe to integrate epidemiological, biological, and clinical approaches, to consider opportunities to “birth” observational studies from intervention studies, or conversely, to embed interventions within observational studies. Community interventions such as ACTIVE, REACH, or more recently, the Experience Corps evaluation, could create an important opportunity for one kind of gene-environment interaction study – the intervention “treatments” are unusually well characterized (and randomly allocated) aspects of the environment. Large behavioral or clinical intervention trials produce very detailed data on participants, who may be well motivated to participate in further research. Alternatively, large cohort studies with rich biological data such as CARDIA and MIDUS may provide excellent opportunities to select participants for a randomized clinical trial based on earlier characteristics. Whether creating experimental studies from observational cohorts or vice versa, the above mentioned studies have great potential to illuminate the biological pathways related to psychological and social processes, and to identify interactions between physiological and environmental processes.

Recommendation 4: The NIA/BSR should support efforts to track population trends and disparities, particularly for cognition and disability as well as cause-specific mortality and morbidity, mental disorders, work, income, and wealth.

The NIA/BSR should focus efforts on describing trends, measuring determinants, understanding causal mechanisms, and documenting consequences for the key aging-related variables of cognition and disability (including prevalence, incidence, and age at onset). The use of life course studies will be paramount for understanding the genesis of health disparities in older ages, as well as frailty and disability.

The Committee identified cognition as an independent variable affecting many outcomes of interest to social and behavioral researchers; nonetheless, little is understood about cognitive change over time or why some older adults have high cognitive performance while others experience decline. Given the dearth of information in this area, the Committee recommends that the NIA/BSR support studies of trends and variation in cognitive performance, as well as the determinants of cognitive change, their mechanisms, and biological pathways. The NIA/BSR also should support collection of better data on: early predictors of high cognitive performance, cognitive impairment, and preclinical dementia; socially situated cognition (e.g., decision-making in a family context) and collective intelligence; and context and diurnal variation in cognition. Especially needed are data on cognitive trajectories in midlife; also desirable is at least one study of cognitive development over a significant part of the adult life span, linked to rich social and economic data, with data fully available for sharing among investigators.

NIA/BSR-funded studies should include richer and earlier measures of preclinical disability, disability onset and recovery, changing living situations, perceptions of aging, assistive technology, and environmental barriers. Positive aspects of aging (civic engagement, volunteerism) should be captured as well as aging-related deficits. Measures common across studies should include those adopted by the U.S. Food and Drug Administration as outcomes.

The Committee underscored the importance of having a data infrastructure to support studies of disability dynamics and trends. They urged NIA/BSR to consider a range of design options, including adding on to an existing longitudinal survey; initiating a new longitudinal study or repeated cross-sectional data collection with clear goals; or extending the NLTCs with modifications. The Committee agreed with the conclusion voiced at recent Expert Meetings on the Future of the NLTCs, that conducting measurement every five years is inadequate for studying transitions among disability states and living situations. The Committee recommended more frequent data collection and event-based sampling, among other options.

To permit meaningful analysis of within-group differences and health disparities along these dimensions, the BSR should encourage increasing sample sizes of racial/ethnic groups (such as Hispanics and Asian Americans, as well as African Americans), giving particular attention to selective retention in longitudinal studies. The aim should be to make greater disaggregation within these heterogeneous racial/ethnic groups possible in analyses.

The Committee expressed alarm that, because of budget shortfalls, the NCHS may terminate the full collection of vital statistics data and move toward sampling-based statistics. The Committee urged the NIA, in conjunction with the NIH, to voice serious concern that doing so would result in the loss of vital statistics data (on births, deaths, marriages) and will negatively affect the nation's ability to monitor trends in these events across age and racial/ethnic groups.

Recommendation 5: The NIA/BSR should fund research on innovative approaches for collecting data.

The NIA/BSR should support testing of innovative measurement techniques with subsamples of large, population-based surveys; for example, intensive measurement strategies proximal to when survey data are collected (e.g., momentary self-reports [Experience Sampling Method (ESM) or Ecological Momentary Assessment (EMA)], activity monitoring) and modern psychometric techniques that reduce respondent burden and increase measurement efficiency. Technology-driven data collection modalities also could feature significantly in future survey research – e.g., online data collection, electronic diaries, inactive voice response (IVR), image-based rendering, and telemedicine techniques. The Committee also encouraged the NIA/BSR to explore the value of neuroimaging and experimental measures, possibly on subsamples of the larger studies.

Measuring important variables such as cognition in the context of surveys historically has increased respondent burden and reduced comparability among datasets. However, the Committee anticipated that the widespread use of item response theory (IRT) to facilitate computer-adaptive testing, as well as the development of new validated short-form measures, will increase the feasibility of measuring these variables in a greater number of datasets. They

recommended that NIA/BSR monitor the NIH Patient-Reported Outcomes Measurement Information System (PROMIS) and other efforts, to encourage the application of IRT in domains that are relevant to aging research.

In addition, the NIA/BSR should facilitate development of common measurement batteries for cognitive variables. They also should foster greater linkages across datasets and promote training in how to use such linkages for research purposes.

It is critical to link administrative data from the Centers for Medicare and Medicaid Services, Social Security Administration, and other sources, in order to enhance the value of the already rich datasets funded by NIA/BSR. The NIA/BSR should continue coordinating with relevant Government agencies to overcome linkage barriers and foster efforts to increase respondent cooperation in permitting these linkages for research purposes.

Recommendation 6: The NIA/BSR should fund innovative approaches for disseminating data on individuals and increasing use of survey data by new investigators for research purposes.

The rich phenotypic and environmental data characteristic of behavioral and social research studies that are linked with genetic data comprise unique and highly sensitive datasets; this has generated ongoing concerns about data confidentiality and study participant privacy. While valid, these concerns tend to limit data access. Therefore, the Committee recommended that the NIA/BSR support efforts to foster data sharing and accessibility. One Committee-endorsed approach would be to license users to access only restricted microdata files. To facilitate data access for research purposes, the NIA/BSR also should continue to support data enclaves and restricted data centers, such as those of the National Center for Health Statistics and the U.S. Census Bureau. They also should consider expanding data enclave support to other institutions and enlarge the number of secure sites for confidential level data.

In the longer term, the NIA/BSR should ensure that the unique issues surrounding genetic data in behavioral and social research are addressed in institutional confidentiality and privacy policies. NIA/BSR staff should work with investigators on data collection projects to ensure that informed consent forms are written broadly enough to permit secondary analysis (consonant with the requirements of institutional review boards). NIA/BSR staff should continue efforts to prepare guidelines on acceptable data sharing plans for data sets which include both rich social and behavioral data and genetic and other biological data. These guidelines should accord with the more general guidelines being developed by NIH, but should provide more specific guidance for the kinds of data linkages found in NIA/BSR-funded studies.

To increase the use of publicly available data, the NIA/BSR should support efforts to improve data documentation and to make complex datasets more user-friendly and navigable by less experienced researchers. The recent overhaul of the PSID dataset is a success story in this regard. In addition, the NIA/BSR should support creative approaches to marketing datasets to a new generation of researchers. These efforts could include training sessions at summer institutes and conferences, grants for education projects, online tutorials, “dataset Wikipedias,” and other cost-effective efforts to realize an even greater return on NIA data investments.

Appendix A

MEMBERS OF THE COMMITTEE ON DATA PRIORITIES FOR BEHAVIORAL AND SOCIAL RESEARCH ON AGING

Lisa Berkman, Ph.D. (Co-Chair) is an epidemiologist and a professor of public policy at the Harvard School of Public Health. She spent the first part of her career using community-based studies to look at how social factors, particularly isolation and inequality, impact health outcomes, primarily cardiovascular disease and stroke. For the last ten years, she worked on clinical trials to intervene and change social and behavioral factors in order to improve health. Most recently, she is studying the degree to which occupational histories and exposures impact health and functioning in post-retirement and the implications of occupational policy for an aging society.

James Smith, Ph.D. (Co-Chair) is an economist at RAND Corporation. His current research focus is the interaction between economic status and health, and his recent work addresses international differences in health and economic status. Due to his involvement with the Panel Study of Income Dynamics, the Health and Retirement Study (HRS), and international efforts to create studies similar to the HRS, Dr. Smith has taken an active interest in data infrastructure.

Thomas Cook, Ph.D. is a social science methodologist. He is Professor of Sociology, Psychology, Education, and Social Policy at Northwestern University, where he is the Joan and Serepta Harrison Chair in Ethics and Justice.

Eileen Crimmins, Ph.D. is the Director of the University of Southern California/University of California, Los Angeles Center on Biodemography and Population Health, where she is the Edna M. Jones Professor of Gerontology. Her research often is conducted at the intersection of biology and demography.

Linda Fried, M.D., M.P.H. is an epidemiologist and geriatrician at Johns Hopkins University. Her current work on a community-based intervention to decrease frailty, disability, and falls in older adults is part of a larger senior volunteer program, Experience Corps, whose goal is to harness the social capital of an aging society.

James Jackson, Ph.D. is a social psychologist and Director of the Institute for Social Research at the University of Michigan.

Graham Kalton, Ph.D. is a survey statistician at Westat, Inc. His research interests include all aspects of survey research, with an emphasis on survey sampling, panel surveys, and compensating for missing data. He recently participated in a U.K. Economic and Social Research Council review of the future needs for longitudinal survey data in the United Kingdom.

David Laibson, Ph.D. is a professor of economics at Harvard University. Dr. Laibson studies the psychological factors that influence economic behaviors.

Jack McArdle, Ph.D., a quantitative psychologist at University of Southern California, studies longitudinal dynamics in panel data. The context for his research is the area of cognition. He has recently worked with HRS in an effort to bring more psychometric concepts and robust measurements of cognition into survey research.

Samuel Preston, Ph.D. is a professor of demography and sociology at the University of Pennsylvania. His primary research area is mortality. Recent studies include the effect of cigarette smoking on U.S. mortality differentials in the 20th century, life tables for African Americans, and how to decompose differences in life expectancy by cause of death.

Jonathan Skinner, Ph.D. is an economist and Professor of Community and Family Medicine at Dartmouth College and Medical School. He works with Medicare claims data and also is involved in a clinical trial on back surgery. Dr. Skinner is interested in matching Medicare claims data at the hospital or provider level to HRS, in order to provide measures of healthcare quality for each survey participant.

Arthur Stone, Ph.D. is a psychologist whose research career includes measuring stressors and coping. He is involved in improving self-report measures as part of the PROMIS Roadmap Project, with the goal of developing more intensive measurement strategies for surveys.

Kenneth Wachter, Ph.D. is a demographer at the University of California, Berkeley. His specific areas of interest include mathematical demography, biodemography, and evolutionary demography. He also chairs the National Research Council Committee on Population, which recently has been looking at bioindicators, and a number of his students are working with BSR data sets.

David Wise, Ph.D. is an economist at Harvard University. He directs the Program on the Economics of Aging, as well as an international program on Social Security and retirement programs.

Appendix B
SEPTEMBER 2006 MEETING BINDER CONTENTS

- 1. Agenda**
Participant Roster
- 2. Charge to the Committee**
- 3. Overview**
 - Data Sets Used by Articles Included in "Science Advances" Section of BSR Sourcebook
 - Future Plans in the Federal Statistical System (DRAFT-uncorrected 9/18/06)
 - Federal Interagency Forum on Aging-Related Statistics, Data Sources on Older Americans 2006 (Draft in progress 8/9/06)
 - Suzman R. Planning and Funding Longitudinal Studies in Centralized and Decentralized Statistical Systems. Proceedings of the Conference on Longitudinal Social Surveys in an International Perspective; 2006 January 25-27; Montreal, Canada.
 - Major BSR-Funded Data Sets. Administrative Document. National Institutes on Aging, 2006.
 - Approximate Budgets for Major BSR Data Projects, FY2006
- 4. Cross-National Research**
 - Haaga J. Data for Cross-National Research – Background. Memorandum to Committee on Data Priorities for Behavioral & Social Research on Aging, August 23, 2006.
- 5. NIA Data Archiving Projects**
 - NIA Data Archiving Projects. Administrative Document. National Institutes on Aging, 2006.
 - Gutmann M. Factors in Aging—Development Research Resources. Abstract of Grant Number P30 AG004590-17. Accessed from NIH Query/View/Reporting System on September 12, 2006.
 - Gutmann M. Human Subject Protection and Disclosure Risk Analysis. Abstract of Grant Number P01 HD045753-03. Accessed from NIH Query/View/Reporting System on September 12, 2006.
 - Excerpts from PA-06-465: Longitudinal Surveys of the Elderly: SBIR Initiative (R43/R44). Available at: <http://grants.nih.gov.grants/guide/pa-files/PA-06-465.html>
 - Data Sharing for Demographic Research [homepage on the Internet]. Ann Arbor: Institute for Social Research [cited September 11, 2006]. Available at: <http://www.icpsr.umich.edu/DSDR/>
- 6. Life Course Studies**
 - Barker D. The Helsinki Cohort.
 - Reiss D. New Life for Developmental Studies and Aging.
 - Profiles of National Longitudinal Surveys
- 7. Disability Dynamics**
 - National Long-Term Care Survey (NLCTS). Prepared for BSR Data Advisory Meeting. September 11, 2006.

8. Mortality

- Description of the National Longitudinal Mortality Study (NLMS)

9. Retirement and Health Economics

- Specific aims from Health and Retirement Study, 2006-2011, excerpted from grant application (Robert J. Willis, Principal Investigator)
- Report of the Ad Hoc Advisory Panel to the Behavioral and Social Research Program. Recommendations to the NIA Extramural Program on Priorities for Data Collection in Health and Retirement Economics, Executive Summary. National Institute on Aging, Administrative Document, May 1988.

10. Biomarkers and Genetics

- Chicago Core on Biomarkers in Population-Based Aging Research [homepage on the Internet]. Chicago: The National Organization for Research at the University of Chicago; c2005 [cited 12 September 2006]. Studies Collecting Biomarkers; [1 screen]. Available at: <http://biomarkers.uchicago.edu/studiescollectingbiomarkers.htm>.
- McDade T, Williams S, Snodgrass J. What a Drop Can Do: Expanding Options for the Analysis of Blood-Based Biomarkers in Population Health Research [Draft—conclusions and tables only]. Proceedings of the 71st Annual Meeting of the Population Association of America; 2006 30 March–2 April; Los Angeles, California.

11. Cognition

- Haaga J. Data Sets for Study of Cognitive Aging. Memorandum to Committee on Data Priorities for Behavioral & Social Research on Aging, September 12, 2006.
- Willis R. Aging in the U.S.: The Health and Retirement Study [excerpted]. Presented at the Conference on Longitudinal Social Surveys in an International Perspective; 2006 January 25-27; Montreal, Canada.
- Langa KM, Plassman BL, Wallace RB, Herzog AR, Heeringa SG, Ofstedal MB, et al. The Aging, Demographics, and Memory Study: Study Design and Methods, *Neuroepidemiology*. 2005;25:181-191.

12. Recommendations from the National Academies of Science

- Recommendations Relevant to NIA/BSR Data Priorities from Recent Reports from the National Academies

Appendix C
MAY 2007 MEETING BINDER CONTENTS

- 1. Agenda**
Participant Roster

- 2. Charge to the Committee**
September 2006 Committee Meeting Summary

- 3. Cohort Studies**
 - Haaga J. Background on Cohort Studies. Memorandum to NIA Committee on Data Priorities for Behavioral and Social Research on Aging. May 9, 2007.
 - Li RM. HRS Methods of Adapting to New Content and Opportunities. Memorandum to NIA Committee on Data Priorities for Behavioral and Social Research on Aging. May 7, 2007.
 - Seematter-Bagnoud L, Santos-Eggimann B. Population-based cohorts of the 50s and over: a summary of worldwide previous and ongoing studies for research on health in ageing. *Eur J Ageing*. 2006;3;41-59.
 - Brim OG, Baltes PB, Bumpass, LL, et al. NATIONAL SURVEY OF MIDLIFE DEVELOPMENT IN THE UNITED STATES (MIDUS), 1995-1996 [Computer file]. ICPSR02760-v4. Ann Arbor, MI: DataStat, Inc./Boston, MA: Harvard Medical School, Dept. of Health Care Policy [producers], 2007. Ann Arbor, MI: Inter-university Consortium for Political and Social Research [distributor], 2007-04-16.
 - Hauser RB, Sewell WH, Little JK. WISCONSIN LONGITUDINAL STUDY, 1957, 1964, 1975, 1977, 1992-1993, AND 1993-1994 [WAVE III DATA, 1993-1994] [Computer file]. ICPSR06163-v1/1st WLS ed. Madison, WI: Robert M. Hauser, William H. Sewell, and J. Kenneth Little, University of Wisconsin [producers], 1997. Madison, WI: Data and Program Library Service [distributor], 2006-04-12.
 - Coverage of 1900-1965 Birth Cohorts in Various Longitudinal Surveys at Specific Ages. Figure.

- 4. International and Cross-National Research**
 - Lee J. Executive summary of NIA Scientific Meeting on Harmonization of Aging Surveys and Cross-National Studies of Aging. Chiang Mai, Thailand. February 24–27, 2007.
 - Recommendations From Recent NAS/IOM Reports Concerning Data Priorities for Cross-National Research on Aging. Administrative Document. National Institutes on Aging, 2007.

- 5. Cognition and Personality**
 - Committee on Data Priorities for Behavioral and Social Research on Aging Subgroup on Cognitive Data Needs. Teleconference Report. May 1, 2007.
 - McArdle J. When You're 64. . . . *APA Online: Psychology Science Agenda*. 2007;22(3). Available at: http://www.apa.org/science/psa/mcardle_prnt.html.
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6. Biomarkers and Genetics

- Committee on Data Priorities for Behavioral and Social Research on Aging Subgroup on Genetics Data Needs. Teleconference Report. May 10, 2007.
- Recommendations From Recent NAS/IOM Reports Concerning Data Priorities for Research in Genetics and Social Behavior. Administrative Document. National Institutes on Aging, 2007.

7. Disability Dynamics and Frailty

- Hamilton E. Nursing Home and Home Health Agency Data. Memorandum to NIA Committee on Data Priorities for Behavioral and Social Research on Aging. May 7, 2007.
- Patmios G. Current Status of the National Long Term Care Study (NLTC). Memorandum to NIA Committee on Data Priorities for Behavioral and Social Research on Aging. May 7, 2007.
- Expert Meeting on the Future of the National Long-Term Care Survey: Data Needs for Disability Policy Making and Research for the Future. National Institute on Aging Meeting Summary. Prepared by Rose Li and Associates, Inc. October 7, 2005.
- Expert Meeting on the Future of the National Long-Term Care Survey. National Institute on Aging Meeting Summary. Prepared by Rose Li and Associates, Inc. February 14, 2006.
- Committee on Disability in America Board on Health Sciences Policy (Field MJ, Jette A, eds.). *The Future of Disability in America*. Washington DC: The National Academies Press. *Prepublication Copy*.
- Recommendations From Recent NAS/IOM Reports Concerning Data Priorities for Research on Health Disparities and Older Populations. Administrative Document. National Institutes on Aging, 2007.

8. Data Sharing

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- Recommendations From Recent NAS/IOM Reports Concerning Data Sharing. Administrative Document. National Institutes on Aging, 2007.
- Straf ML. National Academies Studies on Privacy and Confidentiality. Synopsis of relevant work, May 9, 2007.
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9. Federal Perspectives

- Sondik, E. Thoughts on Data Priorities for Behavioral and Social Research. Powerpoint slides from presentation to the NIA Committee on Data Priorities for Behavioral and Social Research on Aging. May 21, 2007.

10. Data Dissemination and Archiving

- Major BSR-Funded Data Sets. Table. Administrative Document. National Institutes on Aging, 2007.
- Schoeni, R. Facilitating Data Use in the PSID. Administrative Document. National Institutes on Aging, 2007.

- The National Archive of Computerized Data on Aging. Brochure. The Interuniversity Consortium for Political and Social Research. University of Michigan.
- Recent Additions to NACDA Holdings.
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- Survey of Income and Program Participation (SIPP) Tutorial Roadmap: The Quick Reference Guide. U.S. Census Bureau Web site, Demographics Survey Division. Available at: <http://www.sipp.census.gov/sipp>.

Other Handouts

- Allison Rosen and David Cutler, "Expanding the U.S. National Health Accounts to Measure Productivity," Powerpoint slides from presentation to the National Academies Panel to Oversee a Research Program on the Design of National Health Accounts, May 17, 2007.
- Richard Suzman's Powerpoint slides on BSR cross-cutting principles, areas of emphasis, current initiatives and workshops
- Haaga, J. Publications Using BSR-Funded Data Sets as an Indicator of Successful Dissemination. DRAFT Memorandum to NIA Committee on Data Priorities for Behavioral and Social Research on Aging. May 18, 2007.